

NJR Privacy Notice

Why the data is collected

The National Joint Registry for England, Wales, Northern Ireland, and the Isle of Man (NJR) collects data about hip, knee, shoulder, elbow, and ankle joint replacement surgery. The purpose of collecting the data is to monitor the performance of orthopaedic implants, surgical teams, and hospitals in order to improve the outcomes of joint replacement surgery and to ensure patient safety. The aims and goals of the NJR are set out in its strategic plan and are summarised on its website at: <http://www.njrcentre.org.uk/njrcentre/AbouttheNJR/tabid/73/Default.aspx>.

What personal data is collected?

In order to achieve its aims, the NJR needs to collect patient identifiable data so that it can link primary or first operation, joint replacements to revision, or second operation, procedures for the same patient. Being able to link primary and revision operations for the same patient is essential if the NJR is to meet its strategic goals.

The personal data collected by the NJR for each patient includes:

- Forename
- Surname
- Gender
- Date of Birth
- Postcode
- NHS Number or, in Northern Ireland, Health and Care Number

This data is used to link primary and revision procedure records for an individual patient and items, such as gender and date of birth, enable the NJR to undertake additional analysis such as the outcomes of joint replacement surgery for different age groups.

The NJR also collects a patient's address and date of death. The former enables the NJR to invite patients to take part in clinical audits and, where appropriate consent is given, research projects. The date of death, along with the date of any revision procedure, is essential to calculate the outcomes of surgery.

Patient Consent

The NJR will only collect personal data with a patient's consent. Before an operation, patients should be offered an NJR consent form and patient information leaflet, both of which explain why the NJR collects patient data, what data is collected, how it is used, and how it is protected. The consent form and patient information leaflet can be found at:

<http://www.njrcentre.org.uk/njrcentre/Healthcareproviders/Collectingdata/Patientconsent/tabid/101/Default.aspx>

Patients do not have to give consent for the NJR to hold their personal data and if a patient decides to withdraw previously given consent they can do so at any time by contacting the NJR Centre using the contact details provided below. If a patient withdraws consent, all personal details will be deleted from all records relating to that patient.

The NJR also collects personal details where consent is recorded as unknown, i.e. a patient has not been asked to consent. This does not happen in many cases and the NJR has permission to collect details for these records under Section 251 of the NHS Act 2007 in the interests of ensuring patient safety and patient outcomes. Patients for whom consent is recorded as 'unknown' will not be contacted by the NJR nor invited to take part in any follow up study or research projects.

How is the data processed?

All data collected by the NJR is stored in a secure facility, with personal data encrypted on the database. All data is accessible only to a very limited number of NJR Centre staff. Although personal data is used to undertake analyses, all outputs are aggregated so that individual patients cannot be identified.

The NJR also has permission under Section 251 of the NHS Act 2007 to use patient identifiable data to link to other health datasets. Currently, these include:

- The Hospital Episodes Statistics (HES) service.
- The Patient Episode Database Wales (PEDW) service.
- The NHS England Patient Reported Outcomes Measures (PROMs) service
- Data from the Office of National Statistics
- Data from the Department of Health Information and Analysis Directorate, Northern Ireland (planned).

The purpose of linking to these data sets is to enhance the type of analyses undertaken by the NJR. Linking to data that has already been collected saves hospitals having to provide the same information more than once to different organisations.

Once the datasets have been linked, the data is pseudo-anonymised by removing all patient identifiers. Again, the outcomes of all analyses are aggregated so that individuals cannot be recognised: record, or individual-level, data is not published.

The release of data is subject to strict controls and patient identifiable data will only be released for fully approved research projects where the NJR Centre has sought appropriate consent beforehand.

What information does the NJR publish?

The NJR publishes data for a range of different stakeholders in a variety of different places. Some secure services are available for surgeons, suppliers, and hospital management. Surgeons can only see information about procedures that they have carried out, and suppliers and hospital management do not have access to record level detail. This means that suppliers and management cannot identify patients.

Publicly available information can be found at:

- www.njrcentre.org.uk. Much of the information contained in this notice can be found on the NJR's main website. The website also includes external links to other information about joint replacement.
- <http://www.njrreports.org.uk>. This website provides information about the work of the NJR and includes reports about joint replacement activity over the life of the NJR. This website is updated annually with more features and reports being added at regular intervals. Also available from the website are the NJR's Annual Reports, which include clinical analyses, and Patient Guides for each of hip, knee, shoulder, elbow, and ankle joint replacement.
- <http://www.njrsurgeonhospitalprofile.org.uk/>. The NJR publishes consultant and hospital outcomes information as part of the government's Clinical Outcomes Programme. Although the publication is mandatory for consultants and hospitals in England, consultants in Wales and Northern Ireland can choose to have their data published. The data is also published on the NHS Choices website (<http://www.nhs.uk/pages/home.aspx>).
- <http://www.njrcentre.org.uk/njrcentre/Research/ResearchPortfolio/tabid/313/Default.aspx>. The NJR publishes details of the research and analysis projects that it undertakes. This work is undertaken by the NJR and external organisations. Analyses include the use of NJR data only or the use of datasets derived from linked data. Current permissions mean that the analysis of linked datasets can only be undertaken by the NJR but the NJR does allow analysis of NJR-only data to be undertaken by external organisations. The release of all data is subject to strict controls and does not include any data that would enable researchers and analysts to identify individual patients.

Who controls the use of the data?

The NJR is part of the National Clinical Audit and Patient Outcome Programme (NCAPOP) which is delivered by the Healthcare Quality Improvement Partnership (www.hqip.org.uk). For the NJR, HQIP acts as the data controller and is responsible for how the data is used. In deciding who can have access to the data, HQIP has a clearly defined approvals process which involves a group with clinical, information governance, patient confidentiality, data protection, and legal expertise. The release of any data is subject to rigorous controls and, as stated previously, personal data would only be released for research where a project has received the appropriate approvals and individuals have been contacted by the NJR and asked to for their consent to take part. For further information about approvals for research projects, please visit www.hra.nhs.uk.

Who processes the data?

The data is processed by Northgate Public Services (UK) Ltd (NPS). NPS is contracted by HQIP to provide the data collection, aggregation, and reporting services for the NJR. NPS provides the NJR Centre staff and is certified to international standards for information security, information management, and data processing. In addition to providing the data entry application and the facilities for storing and protecting the data, NPS also provide the online

reporting services. A very limited number of staff have access to the data. It is NPS staff who undertake the linkage of NJR data to other datasets and who provide data for analysts following approval from HQIP. For further information about NPS please visit:

<https://www.northgateps.com/sectors/healthcare/>

The other NJR data processor is the University of Bristol whose specialist staff provide statistical and analysis services for the NJR. They are provided with data, both NJR-only and NJR-linked data, by NPS for all analysis projects, including the annual report data set. The data provided to the University does not contain personal information and all published data is aggregated. Even as a data processor, the team at the University of Bristol does not have regular access to patient identifiable information for NJR data and has no access to patient identifiers for linked datasets.

Do I have to provide my personal information to the NJR?

Patients do not have to consent to the NJR holding their personal information. However, the NJR will not be able to meet its aims of improving the outcomes of joint replacement surgery and improving patient safety if patients do not provide their consent.

If, having originally given consent, the NJR can provide patients with all their NJR record. For further information about requesting the data that the NJR holds about you please visit the NJR website:

<http://www.njrcentre.org.uk/njrcentre/Patients/AccessingyourNJRdata/tabid/211/Default.aspx>

If a patient, having granted consent, wishes to withdraw that consent can contact the NJR and ask for their personal information to be removed from the NJR database. The NJR will retain a record of the operation which will not include any information that could identify a patient. Such a record cannot be linked to any other procedures for the same patient, will not be used in any analyses, and cannot be used to enable the NJR to identify any patient to a hospital in the event of issues being identified with their implants.

If patients wish to either obtain data about them held by the NJR or withdraw consent they should contact the NJR using the following contact details:

Email: enquiries@njrcentre.org.uk

Phone: 0845 345 9991

Address: The NJR Centre,
c/o Northgate Public Services
Peoplebuilding 2,
Maylands Avenue,
Hemel Hempstead,
HP2 4NW